

Grand Forks Session – Comments From Participants

How did you find out about the focus group?

- DD case manager
- Independent Living Centers should be contacted in future
- Email – family voices
- Public health
- NE human service center

How do you access information about programs and services?

- PACER – publication from MN – produced by Pacer – like Pathfinders in ND
- Family Voices
- Family
- DD case mgr.
- Infant development or public health care nurse
- ARC
- NDAD
- Options
- If you want useful info for your kids it's hard to find – general info is easy to find
- You don't hear about financial help – can't get info very easily locally
- Entities (parents) get frustrated when they don't get an answer – or a right answer
- At the local level we can't get info
- Dealing with gov't is difficult – redundant with info needed to provide best care
- Hard to get the medical community to listen
- They say you'll always be denied on paper the first time
- Get burnt out very fast – if you have a good DD case mgr., that helps
- County Social Services – good in north part of state, but it's not up to date with programs
- New parents need an advocate – some case mgrs. don't know anything
- Parents need to be proactive in gathering info
- Need an all-encompassing document with all resources
- Special Ed. Depts. in schools are a real challenge
 - o They can't have summer programs because they can't prove regression
 - o Schools aren't prepared for special needs kids – don't have the money – federally mandated program but no money
 - o Until teachers have a child with the disorder, you have to be their teacher
 - o You have no choice – you have to teach them because they don't know

How do you access information about programs and services?

- Special Ed coop – parents want their kids to stay in their home school district rather than busing them to larger town
 - o Kids graduate then go home and have not friends, no socialization with the home community
- Families don't know about expensive equipment not being used that could be given to other families – need a better network
- We ask for medical assistance and repeatedly get denied
- People fall through the cracks who have no credit to get loans and in turn get reimbursed – here's where they need a DD case manager
- Parents are the care coordinators
- Need to educate providers on what parents need
 - o Physicians are listening to patients more

What services are lacking in communities?

- pediatric neurology – we lost one out of Fargo
- a majority of my doctor care is in Minneapolis – we've gotten so much more care there
- doctors haven't told me certain things – I've had to read it in my child's file]
- Medicaid denied our son going to Mayo when the doctor recommended it
- If the specialist says the child should go to Minneapolis, Medicaid should pay for it
 - o It seems like Medicaid thinks it's better for them to die at this point
- Respite comes, but not when you're at work
- We need daycare – what do they do from age 12 to 18? Couldn't we get rid of respite care and go to aged care?
- Have to give up my kid to get him service or more to Minnesota

After hours notes

- They say school isn't socialization – that's untrue – socialization is a big part of kids with disabilities
- Grand Forks has good transition program from 14-21, but in Cavalier, it's not like that
 - o There's a divide in services from 18 to 21 up north if they graduate at age 18
- It almost depends on who you are and who you know as to what you get
- If you make waves as a parent you'll be branded and discriminated against
- When you give your child up to adult care, you don't have control any more – don't know how they're doing

Role of Children's Special Health Services Program (CSHS) – have you received support from this?

- Depends upon case manager – things go well with a good case manager
- Would like to see more PT – only get it once a week and I do the rest
- Need care coordinator – parents are overwhelmed
- Need more emotional support for parents

What's one recommendation you have for improving care?

- getting medical equipment approved
- more respite care
- Doctors and nurses and the state need to be educated from us as parents as to what we go through
 - o Some nurses don't know how to do things for my son – I sometimes have to tell them
- financial help and manage ourselves
- MA – label some things so they don't have to find it – find a way to deny it
 - o Things are coded to get help – ex. Personal hygiene cleansing cloths are covered but not diaper wipes
- Dr. Sobus – physiatrist – wonderful – the state denies her requests also
- The only thing that changes over the years is the type of battle
- Other parents don't know to keep fighting against certain things